NATIONAL SPINA BIFIDA PATIENT REGISTRY – Mortality Form

Funded by the Centers for Disease Control and Prevention
FOA# DD-08-001

Patient

Last Name_____ First Name _____

GENERAL INFORMATION

Date form completed

☐☐ Month ☐☐ Day ☐☐☐☐ Year

Unique ID ☐☐☐☐☐☐☐☐☐☐

DEMOGRAPHIC INFORMATION

1. Patient Age:

Years ☐☐☐

2. Sex:

- ☐ Male
- ☐ Female

3. Date of Last Visit:

☐☐ Month ☐☐ Day ☐☐☐☐ Year

4 a. Primary Race:

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ American Indian/Alaskan Native
- ☐ Other _____
- ☐ Refused
- ☐ Unknown

b. Secondary Race:

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or other Pacific Islander
- ☐ American Indian/Alaskan Native
- ☐ Other _____
- ☐ Refused
- ☐ Unknown

c. Ethnicity:

- ☐ Non-Hispanic or Latino
- ☐ Hispanic or Latino
- ☐ Refused

MORTALITY INFORMATION

5. Date of death:

☐☐ Month ☐☐ Day ☐☐☐☐ Year

6. Information source(s):
(Check all that apply)

- ☐ Death certificate
- ☐ Patient's physician
- ☐ Patient's family
- ☐ Other _____

7. Was an autopsy performed?

- ☐ Yes
- ☐ No
- ☐ Unknown

7a. If an autopsy was done, check type:

- ☐ Partial autopsy without brain
- ☐ Complete autopsy with brain
- ☐ Brain autopsy only
- ☐ Unknown

8. Primary cause of death? (Check one)

- ☐ Cardiovascular Disease-related
- ☐ Renal failure
- ☐ Infection-related

Site(s) of infection:

- ☐ Shunt
- ☐ Kidney
- ☐ Lung
- ☐ Blood
- ☐ Unknown
- ☐ Other _____

- ☐ Respiratory-related
- ☐ Shunt-related
- ☐ Unknown
- ☐ Other

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FORM INSTRUCTIONS

Form Completion: Complete this form upon notification of the death of any patient who received care in the Spina Bifida (SB) clinic and was enrolled in the SB Registry.

Date Form Completed: Enter the date that this form was completed using leading zeros before a single-digit month/day..

Unique ID Number: Enter the unique ID number generated for each patient by the SB Patient Registry Electronic Medical Record.

DEMOGRAPHIC INFORMATION

1. **Patient Age:** Enter the patient's age in years at the date of death using a leading zero for single-digit ages.
2. **Sex:** Check MALE or FEMALE.
3. **Date of Last Visit to This Clinic:** Enter the date the patient was last seen in this clinic using leading zeros before a single-digit month/day.

4a. **Primary Race:** Check the primary race category designated by the patient. Use the OTHER category and write in the information for racial groups not listed. Select the REFUSED category if the patient is unwilling to provide the information. Choose the UNKNOWN category if the information cannot be determined.

b. **Secondary Race:** Check the secondary race category designated by the patient. Use the OTHER category and write in the information for racial groups not listed. Select the REFUSED category if the patient is unwilling to provide the information. Choose the UNKNOWN category if the information cannot be determined.

c. **Ethnicity:** Check the ethnicity category designated by the patient. Select the REFUSED category if the patient is unwilling to provide the information.

MORTALITY INFORMATION

5. **Date of death:** Enter the date of death using leading zeros before a single-digit month/day.
6. **Information Source(s):** Check the source(s) of information used to complete this form.
7. **Was an Autospy Performed:** Check YES, if either a partial or complete post-mortem examination was performed on the patient. Check NO, if no autopsy was performed. Check UNKNOWN, if it is not known.

a. **If an Autospy was done, check type:**
If known, check the type of post-mortem exam conducted. If not known, check UNKNOWN.

8. **Primary cause of death:**
Please categorize the primary cause of death:
   - Cardiovascular-Disease related
   - Renal Failure
   - Infection-related: Check the site(s) of infection
   - Respiratory-related
   - Shunt- related
   - Unknown: cause of death is not known
   - Other: death was a direct result of a known cause not related to the first five groups, please specify